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Nurses' perceptions of their role in discussing end of life issues with patients

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NURSES' PERCEPTIONS OF THEIR ROLE IN DISCUSSING END OF LIFE ISSUES WITH PATIENTS

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ABSTRACT

NURSES' PERCEPTIONS OF THEIR ROLE IN DISCUSSING END OF LIFE ISSUES WITH PATIENTS

by Pegge Hall

This study used a descriptive, cross-sectional design to explore nurses' role perceptions in discussing end of life issues with patients, knowledge of advance directives, and attitudes toward end of life issues. A bioethical theory of moral principles provided the conceptual framework. A convenience sample of nurses (N=26) completed the 39 item questionnaire. Frequencies and percentages analyzed the data.

Findings indicated that, although nurses agreed that discussing end of life issues with patients was within their role, most (85%) discussed these issues only when a patient initiated dialogue. Few nurses (39%) perceived that patients want to discuss these issues, although studies of patients indicate otherwise. Nurses' knowledge of advance directives was low and few (27%) had recommended them to their patients. Additionally, only one nurse had a valid advance directive for personal use.

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Chapter 1

INTRODUCTION

Thousands of Americans will be hospitalized this year after sustaining severe trauma or after a life threatening cardiovascular event; thousands more will develop the insidious mental changes of Alzheimer's Disease. In these cases and many others, including the changes of normal aging, an individual may no longer be able to make his or her own health care decisions. Families, physicians, and, occasionally, the courts will be placed in the difficult position of attempting to determine what the patient's health care wishes would have been.

Since 1984, a tool has been available to competent adults in California that would enable them to specify their health care wishes and to designate a surrogate to make decisions in the event they lose decision making capacity. This legal document is known as the Durable Power of Attorney for Health Care Decisions. Thoughtful consideration of end of life issues and careful use of this document can enable individuals to exercise their autonomy and extend their values into decision making when they are unable to make decisions for themselves (Beauchamp & Childress, 1989).

Nurses' primary obligation toward their patients is expressed in their role as patient advocate; part of the

responsibility of that role includes discussing moral, legal, and ethical issues with their patients (Bigler, 1990). Because nurses spend more time with patients than all other health professionals combined (Buehler, 1990), they are in key positions to educate patients and their families about the use of advance directives such as the Durable Power of Attorney for Health Care Decisions and the Living Will.

This study was designed to explore nurses' perceptions of their role in discussing end of life issues with their patients. Additionally, it was designed to explore nurses' attitudes toward end of life issues and the extent to which nurses were aware of the existence of and uses for the Durable Power of Attorney for Health Care Decisions.

Statement of the Problem

In the last thirty years, medical technology has changed dramatically. Severe illness can be treated, failing organs can be replaced, and people suffering from once fatal cardiopulmonary arrests can often be resuscitated. Although it may appear that medical resources, knowledge, and power to save lives are limitless, there is another side to this medical success. The price of these advances has not only been tremendous financial cost, but the additional cost of human suffering (Sprung, 1990). In some cases a life is saved, but due to a number of unplanned factors, such lives may be filled

with suffering. Other lives may be devoid of pleasure, sensation, or comprehension. Medical technology allows such lives to be sustained indefinitely even when there is no hope of recovery of a meaningful life (Angell, 1990).

Nancy Cruzan was a 32-year old woman who suffered a cardiopulmonary arrest after a 1983 automobile accident, was resuscitated, but suffered severe brain damage due to hypoxia. After four years without evidence of recovery from a persistent vegetative state, characterized by permanent loss of all possibility for experience (Glover, 1990), her family began the legal processes to have her gastrostomy feedings stopped, allowing her to die. This process started in 1987 and ended in 1990 when the United States Supreme Court (Cruzan v. Director, [1990], cited by Lippman, 1991), hearing the first case of its kind, ruled that the state of Missouri did have the right to require that Nancy Cruzan's feeding be continued indefinitely, in absence of clear and convincing evidence that she would have wanted it otherwise. That is, the Supreme Court upheld the state's right to impose restrictions on individual decision making regarding death issues.

Six months later, however, a county probate judge for the state of Missouri did not oppose her parents when they repetitioned the court with further evidence that Nancy Cruzan had stated she did not want her life artificially

prolonged. The tube was removed; Nancy Cruzan died days later (Lippman, 1991).

In the first six months after the United States Supreme Court Decision, the Society for the Right to Die/Concern for Dying, a New York based advocacy organization, received 750,000 requests for Living Will forms--a 50% increase in demand for the documents (Wagner, 1990). The Cruzan decision had obviously heightened public awareness of the need for advance directives. The decision also made it imperative for nurses and other caregivers to broach the sensitive subject of end of life issues with patients before the need for advance directives, that is, before the patient has lost decision making ability (Lippman, 1991).

Because there is no state-to-state uniformity in laws on advance directives and surrogate decision makers, it is essential for nurses to know the laws that concern advance directives in their state. California's Durable Power of Attorney for Health Care Decisions was the first comprehensive advance directive document available to assist individuals in making autonomous choices for their future health care. A study to determine nurses' knowledge about advance directives, role perception in discussing end of life issues with patients, and attitudes toward these issues would be useful in planning educational programs dealing with the nurses' role of patient advocate.

Research Questions

This study sought to elicit information from nurses on issues of role perception, attitudes toward end of life issues, and knowledge of California's advance directives. The following research questions were asked:

1. What do nurses perceive as their professional role in discussing end of life issues with their patients?

2. To what extent are nurses aware of the existence of and uses for the Durable Power of Attorney for Health Care Decisions?

3. What are nurses' attitudes toward end of life issues?

Purpose and Need

The purpose of this study was to describe variables associated with end of life issues. Specifically, the variables were (a) nurses' perception of their professional role regarding end of life issues, (b) nurses' awareness of the Durable Power of Attorney for Health Care Decisions, and (c) nurses' attitudes toward end of life issues. These variables are important because they may influence the way a nurse initiates discussions of these pertinent issues with his or her patients. Further, this information would be useful as a basis for identifying strategies with which to foster in practicing nurses a more theory based commitment to their role as patient advocates.

Murphy (1979) described a patient advocate nurse as one who considers his or her moral authority to be as great as any other health professional and sees his or her first responsibility to the patient as a unique human being. The nurse facilitates the patient's efforts to obtain whatever care is needed, even if it means going against the doctor or hospital administrator. Gadow (1980) stated that existential advocacy is based upon the principle that freedom of self-determination is the most valuable of all human rights and that "existential advocacy, as the essence of nursing, is the nurses' participation with the patient in determining the unique meaning which the experience of health, illness, suffering, and dying is to have for that individual" (p. 81).

As technology advances in nursing and medicine, nurses must maintain and improve their technical skills and knowledge in order to best care for their patients. As these technological advances create potentially agonizing situations for recipients of health care, nurses must also be knowledgeable about legal and ethical issues affecting their patients and must be willing to assist the patients in identifying and documenting their health care wishes in the event decision making capacity is lost. Studies describing end of life issues will be useful in planning programs to address this important aspect of patient advocate focused nursing.

Definition of Terms

For this study, the following definitions were used:

1. End of life issues refer to issues of death and dying, use of life-sustaining treatment, resuscitation status, quality of life, and use of advance directives.

2. Directive to Physicians is more commonly known as the Living Will. The California Natural Death Act of 1976 authorizes adult residents to provide written instructions to physicians to withdraw or withhold life-sustaining treatments in the event of a terminal illness (Martyn & Jacobs, 1984).

3. Durable Power of Attorney for Health Care Decisions (Appendix A) is a legal document that enables an individual to designate someone to make decisions about medical care if he or she should become incapable of making such decisions (Steinbrook & Lo, 1984). An individual can also specify particular health care wishes to be used as a guide for the surrogate decision maker.

Research Design

This study used a descriptive, cross-sectional design to explore role perception, knowledge of advance directives, and attitudes of nurses toward end of life issues. The purpose of this study was to explore nurses' role perception, knowledge, and attitudes regarding end of life issues and the Durable Power of Attorney for Health

Care Decisions document. The sample was composed of 26 nurse volunteers from five adult nursing units at a 250-bed private hospital in central California.

The data collection instrument was a questionnaire with 39 items developed by the researcher with the assistance of a panel of four experts in the field of nursing ethics in California. The members of this panel evaluated the questionnaire for content, test construction, and wording. The questionnaire, entitled "Nurse/Patient Communication Survey," used a fixed response Likert scale to elicit information regarding the three variables of role perception, knowledge of the Durable Power of Attorney for Health Care Decisions, and attitudes toward end of life issues. The remaining 14 questions pertained to demographic data, such as age, religion, highest educational degree obtained, and personal and professional use of the Durable Power of Attorney for Health Care Decisions, and provided additional information about the sample.

Data were gathered by soliciting volunteers from five nursing units who were working on study days. Questionnaires were completed anonymously and were returned to the researcher. Data were analyzed using descriptive statistics, including frequencies and percentages.

Chapter 2

CONCEPTUAL FRAMEWORK AND REVIEW OF LITERATURE

Conceptual Framework

Beauchamp and Childress' (1989) bioethical theory of basic moral principles provided the conceptual framework for the study. It stressed the importance of health care professionals having a moral framework for determining moral obligations to their patients. Because of the technological, scientific, and social developments in the last 50 years that have rapidly changed health care, the concepts of moral obligations of health professionals have become an important component of health care.

Health care workers often find themselves in situations which involve moral dilemmas (Dupre, 1986; Smith & Davis, 1980). Beauchamp and Childress (1989) define moral dilemmas as situations created by conflicting moral principles that generate conflicting demands. The theory of basic moral principles uses four core principles to provide a framework of moral theory that allows health care professionals to identify, analyze, and resolve moral problems. These four principles, which are general action guides for promoting and protecting basic human interests, are the basis of both rights and obligations. They include (a) respect for autonomy, (b) beneficence, (c) nonmaleficence, and (d) justice.

A key facet of Beauchamp and Childress' theory is that each principle is "prima facie" binding, that is, binding in all situations unless there is a conflict with an equal or stronger obligation. If, for example, the principle of respect for autonomy is in conflict with the principle of beneficence in a moral dilemma, the theory delineates ways to analyze and attempt to resolve the dilemma. In a case of conflict, one's moral duty is determined by assessing the obligations of the two competing prima facie duties to determine which produces the greatest balance of rightness over wrongness. Each situation involving moral dilemmas is always unique. This theory allows for discretionary judgment in moral dilemma resolution (Beauchamp & Childress, 1989).

Beneficence

The principle of beneficence stems from the idea that morality is associated with a concern for human welfare. It has been the foundational value in health care ethics (Beauchamp & Childress, 1989) and is mandated in the professional nursing code (American Nurses' Association, 1985).

The ethical principle of beneficence includes the following components: One ought to promote or do good, remove harm, and prevent harm or evil. It requires positive steps to help others. It also obligates one to

weigh and balance the possible good against the possible harm of an action (Davis & Aroskar, 1983).

The primacy of beneficence has had an immense impact on the history of medical ethics, allowing doctors to rely almost entirely on their own judgment about patients' needs. However, in the last 30 years, patients have been asserting their right to make health care decisions for themselves. Patients' values in decision making often differ from physicians' values of curing and healing. So, the primacy of the obligation of beneficence has been challenged by patient-centered ethics that emphasize the rights of autonomy over beneficence whenever they conflict (Bopp, 1990; Dickens, 1987).

Nonmaleficence

The principle of nonmaleficence is the concept that one ought not to inflict harm or cause harm to others (Beauchamp & Childress, 1989). Nonmaleficence requires that health care professionals follow the legal and moral standards of due care in order not to inflict or cause harm to others (Davis & Aroskar, 1983). Although Beauchamp and Childress treat nonmaleficence and beneficence as separate principles, Frankena (1973) discusses nonmaleficence as a component of the principle of beneficence.

Justice

The principle of justice means giving to each person what he or she is due. According to this principle, no

person should be treated unequally, despite differences in persons, until there is proof that the difference between them is relevant to the treatment at stake (Beauchamp & Childress, 1983). The principle of justice implies equal opportunity and fair distribution of treatment and resources (Gortner, Hudes, & Zyzanski, 1984).

Respect for Autonomy

The principle of respect for autonomy states that persons should be free to choose and act without having controlling constraints placed on them by others. The essence of the principle is noninterference (Beauchamp & Childress, 1989; Fowler, 1989). Most people, however, agree that the concept of respect for autonomy does not extend to the harming of other persons or oneself. Additionally, it is relevant only for self-governing, competent persons (Moskowitz & Moskowitz, 1986; Otte & Allen, 1987).

Regarding health care, the principle of respect for autonomy means that individuals have the right to consent to or refuse treatment. Further, health care professionals do not have the right to do anything to patients without their consent. The principle of respect for autonomy provides the basis for the right to make autonomous decisions, the concept of informed consent, and the development of advance directives (Beauchamp & Childress, 1989). In addition, respect for autonomy is mandated by

the professional nursing code (American Nurses' Association, 1985).

Despite its importance, the principle of respect for autonomy, like the three other principles in Beauchamp and Childress' (1989) theory of basic moral principles, has only prima facie standing. Its duties are obligatory unless, in a moral conflict or dilemma, they are overruled by the obligation of a stronger competing principle.

Review of Literature

The review of literature covers (a) conceptualization of ethical dilemmas as conflicts between ethical principles, (b) studies of patients' attitudes about discussing end of life issues, (c) relevant court cases, and (d) recent California laws pertaining to death issues. The conceptualization of an ethical dilemma as a conflict between two ethical principles was described by Beauchamp and Childress (1979) and the four basic principles of bioethics were described. These authors further elaborated on the concepts in 1983 and 1989, incorporating situations from the changing areas of health care, medical law, and societal trends as adjuncts for analysis of ethical dilemmas.

Beauchamp and Childress' (1979) bioethical framework provided the theoretical basis for the work of Gortner et al. (1984) which reported the development of an inventory to measure values in the choice of surgical treatment for

coronary artery disease. This study explored whether one value (of autonomy, beneficence/nonmaleficence, or justice) was considered more important than another by patients and family members. In the study group of 100 patients and family members, autonomy was found to be the dominant value of patients and family members when making decisions about choice of treatment. The researchers recommended that considerable attention be given to patients' and families' needs for information about treatment options and risks versus benefits when surgery is a recommended treatment.

A search of current literature identified no studies of nurses' perceptions of their role in discussing end of life issues with patients. However, two studies focused on patients' attitudes about discussing life-sustaining treatment and documenting end of life decisions. Johnson and Justin (1988) found that patients wanted to talk about end of life issues, wanted to participate in decision making, and did not want to be kept alive if unable to resume a meaningful life. Data showed similar responses regardless of whether the interviewer was a physician or a nurse practitioner. Similarly, Lo, McLeod, and Saika (1986) found that most patients had thought about life-sustaining treatment and surrogate decision makers and that most patients wanted to discuss these issues with physicians, although few had done so.

The right of competent adults to participate in their health care decisions is generally accepted by health care professionals (Moskowitz & Moskowitz, 1986; Otte & Allen, 1987; Sprung, 1990), ethicists (Beauchamp & Childress, 1983), and common law. Justice Cardozo originally articulated this right in the 1914 case, Schloendorff v. Society of N.Y. Hospital (cited in Martyn & Jacobs, 1984), stating "every human being of adult years and sound mind has the right to determine what shall be done with his own body" (p. 781).

Modern law on informed consent affirms the autonomy of competent patients by ensuring that they have the right to consent to or refuse the treatment plan created by the physician (Bopp, 1990; Reardon, 1986). This is a change from the past doctor/patient relationships in which physicians assumed control of decisions.

Within the last 15 years, the courts have affirmed the patient's right to refuse medical care, including life-sustaining care, as a manifestation of a person's constitutional right to privacy (Emanuel, 1987). The best known of these cases involved Karen Quinlan.

The Karen Quinlan Case

The 1976 case, In re Quinlan (cited in Smejkal & Hill, 1990), was the first of several well known cases that set precedence for judicial support for constitutional and common law rights of adults to forego life-sustaining

treatment and has become a landmark case in the evolution of current medical practice. Karen Quinlan was brain damaged and in a persistent vegetative state, maintained by tube feeding and ventilatory support. Her family petitioned the New Jersey Supreme Court and obtained permission to disconnect the ventilator. In comments about the case, the New Jersey Supreme Court noted the following:

> The state's interest (in the preservation of life) weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims. Ultimately, there comes a point at which the individual's rights overcome the state's interest. (p. 51)

The court recognized that other persons could refuse life-sustaining measures on behalf of the affected individual without any formal legal document by the individual specifying his or her wishes.

The Nancy Cruzan Case

Nancy Cruzan was a 32-year old woman who was in an automobile accident in 1983, suffered a cardiopulmonary arrest, was resuscitated and suffered severe brain damage. After remaining in a persistent vegetative state for 4 years, her family petitioned the Missouri courts to have her tube feeding stopped, allowing her to die. The court agreed, but the state of Missouri appealed the case to the Misssouri Supreme Court in 1988.

The Missouri Supreme Court concluded that the state's interest in the preservation of life outweighed the interest of an incompetent patient who was not terminally ill and whose wishes were not clear, at least regarding artificial feeding (Glover, 1990). It reversed the lower court ruling.

With that decision, the Missouri Supreme Court also rejected ethical guidelines and legal precedent indicating that decisions could be based on the best interests of incompetent patients when previous directives were uncertain (Lo, Rouse, & Dornbrand, 1990). In Cruzan v. Harmon (1988), the Missouri Supreme Court held that its interest was not in quality of life, but in an unqualified interest in life, and that outweighed any right invoked on Cruzan's behalf to terminate treatment (Smejkal & Hill, 1990).

The United States Supreme Court heard the 1990 case, Cruzan v. Director (cited in Lippman, 1991). It upheld the state's right to impose restrictions (based on protection of life principles) on individual decision making regarding death issues for the following reasons: (a) The state has a right to assert an unqualified interest in the preservation of life. (b) A choice between life and death is an extremely personal matter. (c) Abuse can occur when incompetent patients do not have loved ones available to serve as surrogate decision makers.

The United States Supreme Court upheld the right of individual states to legislate and regulate in the area of refusing life-sustaining treatment on behalf of another individual. While it supported a conservative approach in Missouri, its ruling also upheld the more liberal approach in California. It left the issue in the hands of the state.

Additionally, the United States Supreme Court affirmed a competent individual's constitutional right to refuse life-sustaining treatment. It also made no legal distinction between tube feeding and other life-sustaining measures. Furthermore, it indicated that individuals who have wishes written in an advance directive have the constitutional right to have them honored (Lippman, 1991).

Advance Directives

The California Natural Death Act (1976) recognized the rights of adults to prepare written instructions authorizing their physician to withhold or withdraw life-sustaining procedures in specified circumstances of terminal illness. The Natural Death Act relieved physicians and health care professionals from civil liability for carrying out the terms of the directive. This Directive to Physicians, also known as the Living Will, is legally binding in California (Davis & Aroskar, 1983; Martyn & Jacobs, 1984).

The Durable Power of Attorney for Health Care Decisions Act was introduced by Senator Barry Keene, who also sponsored the 1976 California Natural Death Act (Martyn & Jacobs, 1984). Under the Durable Power of Attorney for Health Care Decisions Act (1984), an individual can appoint a surrogate decision maker to make health care decisions in the event he or she is unable to make those decisions. These decisions might include consent, refusal, or withdrawal of any treatment, therapy, or service. The proxy could refuse life-sustaining care or, conversely, seek maximal medical care to keep the patient alive. The individual may state particular health care wishes, but the Durable Power of Attorney for Health Care Decisions is valid without additional instructions.

A Durable Power of Attorney for Health Care Decisons continues the surrogate's authority even if the patient is incapacitated. This avoids the need for the courts to make medical decisions or to appoint guardians to make health care decisions (Steinbrook & Lo, 1984).

The use of advance directives, including the Living Will and the Durable Power of Attorney for Health Care Decisions, has been recommended in recent literature (Beauchamp & Childress, 1989; Lo, et al., 1990; Winslade & Ross, 1986) and supported by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1983) and other

consensus groups, such as the Hastings Center (1987). Use of advance directives is a means of extending one's decision making abilities to a possible time of inability to make decisions for oneself.

The ethical principle of respect for autonomy is the basis for informed consent law and for the development of advance directives. Although the principle of beneficence has historically been the primary principle in health care ethics, the literature is recently heavily weighted toward discussions of the principle of respect for autonomy (Brennan, 1988; Dickens, 1987; Jurchak, 1990).

Chapter 3

METHODOLOGY

This study was implemented to explore nurses' perceptions of their role in discussing end of life issues with their patients. Additionally, it was implemented to examine the extent to which nurses are aware of the existence of and uses for the Durable Power of Attorney for Health Care Decisions and nurses' attitudes toward end of life issues.

Research Design

This study used a descriptive, cross-sectional survey design. The researcher-designed questionnaire measured role perception, knowledge of the Durable Power of Attorney for Health Care Decisions, and attitudes toward end of life issues. The rationale for a survey methodology is that complete anonymity of responses is allowed; this is advantageous in dealing with sensitive issues such as death and dying. In addition, the fact that no interviewer is present helps lessen the incidence of interviewer bias (LoBiondo-Wood & Haber, 1986).

Sample and Setting

The target sample group of 30 nurses was designed to include 6 registered or licensed vocational nurse volunteers from each of five adult nursing units at a 250-bed private hospital in central California. On days

the surveys were presented, this researcher selected one of the five designated units and approached nurses individually to briefly explain the purpose of the study. The first 6 nurses from each unit who volunteered to participate were given the packet. At the end of the sampling period, 26 nurses volunteered to participate; all were working on their unit at the time of the survey. The five units were selected for their emphasis on nursing care of the adult patient: critical care, restorative care, neurology, oncology, and medical/surgical care.

Instrument

The instrument used for this study was a 39 question survey developed by the researcher with the assistance of four registered nurses who are experts in the field of nursing ethics in the state of California: a university professor and author of texts on nursing ethics, a consultant for the Center for Aging, a discharge planner for a large hospital and lecturer on nursing ethics, and a nurse/attorney who specializes in medical law. After answering the questions on the initial survey, the members of the panel evaluated the questionnaire for content validity, test construction, and clarity of wording. Appropriate revisions were made. Additionally, two staff nurses answered the questions as a pilot study.

The title of this questionnaire was "Nurse/Patient Communication Survey." Twenty-five questions requested the

participants to respond to statements using a fixed response, Likert scale indicating whether they strongly agree, agree, are unsure, disagree, or strongly disagree. Each of the five levels of agreement or disagreement was assigned a number; participants were instructed to circle the number that most closely indicated their response.

The remaining 14 questions elicited demographic data, such as age, religion, highest educational degree obtained, and information related to personal and professional use of the Durable Power of Attorney for Health Care Decisions. A space was provided at the end of the survey for additional comments regarding the questionnaire and its contents (Appendix B).

Each packet given to the participant included the following:

1. Cover letter entitled: To Participating Nurses.

2. Informed consent form entitled: Agreement to Participate in Research at San Jose State University.

3. Questionnaire entitled: Nurse/Patient Communication Survey.

4. An envelope in which to place and seal the completed survey.

Data Collection Method

Permission to conduct the pilot study was granted by the Human Subjects Institutional Review Board of San Jose State University. Permission was also obtained from the

Director of Nurses of the hospital at which the nurses were working (Appendix C). Nurses who were present on their units on the days the questionnaires were presented were potential participants. A brief explanation of the purpose of the study was given, and the researcher identified herself as a graduate student at San Jose State University working on a thesis project.

It was stressed that participation was voluntary and could be terminated at any time. If the nurse verbally agreed to participate, he or she was given the survey packet, asked to read the cover letter and informed consent, and asked to sign and detach the consent sheet from the questionnaire. Envelopes were provided with each questionnaire, and nurses were instructed to complete the forms, seal in an envelope, and place in a designated box. A separate box was provided for the detached consent sheets, thus assuring anonymity.

The researcher was available on the unit during the completion period to answer questions and to assure safety of the completed response forms. These forms were collected from one unit at a time and remained in the possession of the researcher at all times.

Analysis

Descriptive statistics, including frequencies and percentages, were used to analyze the responses to the items designated to answer the three research questions,

Items 1-25. Three categories were created by adding individual items. Perception of role (items 9-19), knowledge of the Durable Power of Attorney for Health Care Decisions (items 20-25), and attitudes toward end of life issues (items 1-8) show which items make up the three categories.

Limitations

The study was limited by design, instrument, sample, and data collection in the following ways:

1. Cross-sectional design does not permit any assumptions about cause and effect because data were gathered at one point in time.

2. The instrument lacks established reliability and validity since it was developed for this research study.

3. The study was limited by the sample because the sample size was small and came from a small community hospital. Therefore, the sample may not have been representative of nurses in general.

4. Because the sample was asked to volunteer, there may have been some difference between those who volunteered and those who refused to participate. There may also have been a bias toward socially desirable responses among the responders.

Chapter 4

ANALYSIS AND INTERPRETATION OF DATA

Introduction

This study used a descriptive survey design to explore nurses' perceptions of their role in discussing end of life issues with their patients, the extent to which nurses are aware of the existence of and uses for the Durable Power of Attorney for Health Care Decisions, and nurses' attitudes toward end of life issues. The sample consisted of 26 nurses obtained by convenience sampling from five adult nursing units at a private hospital in northern California. The data collection instrument was a 39 item questionnaire which included both Likert type and open-ended questions.

Sample

Most of the sample was female (96%) ranging from 22 to 65 years old (Table 1). The sample was mostly protestant (50%), but 38% were Catholic. The sample was mostly registered nurses (92%) prepared at the BSN (35%) and ADN (31%) level. The data demonstrated a range in years of nursing practice in California from 1 to 32 years. Medical/surgical (35%) and critical care (23%) were the specialty areas in which the largest groups of surveyed nurses were employed.

Table 1

Sample Characteristics (N=26)

	n	%
Gender		
Female	25	96
Male	1	4
Age		
Less than 25	4	15
25-35	9	35
36-45	10	38
Older than 45	3	12
Religion		
Protestant	13	50
Catholic	10	38
None	2	8
Missing	1	4
Education		
Licensed Vocational Nurse	2	8
Diploma Registered Nurse	6	23
Associate Degree Registered Nurse	8	31
Bachelor of Science in Nursing	9	35
Master of Science in Nursing	1	4
Professional Title		
Licensed Vocational Nurse	2	8
Registered Nurse	24	92
Nursing Specialty		
Medical/surgical	9	35
Critical care	6	23
Neurology	3	11
Oncology	2	8
Float to all units	1	4
Missing	5	19

Table 1 (Continued)

Sample Characteristics (N=26)

	n	%
Number of years practiced nursing in California		
1-5	11	42
6-10	7	27
11-15	4	15
16-20	2	8
Greater than 20	2	8
Type of nursing unit		
Restorative care	3	11
Medical/surgical	10	39
Critical care	6	23
Neurology	3	11
Oncology	2	8
Float to all units	1	4
Missing	1	4

Note. Percentages add to more than 100% due to rounding.

Professional Role

The first research question was: What do nurses perceive as their professional role in discussing end of life issues with their patients? To answer this question, frequencies and percentages of responses to items from the survey (Appendix B) that pertained to role (items 9-19) are discussed (Table 2). For simplicity, the agree and strongly agree categories have been collapsed into one category. The same has been done with the disagree and strongly disagree categories.

The majority of nurses (81%) agreed or strongly agreed that discussing end of life issues was within their role, and they were comfortable with such discussions (81%). Even so, 42% agreed or strongly agreed that they did not initiate end of life discussions with their patients, and the majority (85%) reported that they discuss these issues only when patients indicate a desire to do so.

Almost all the nurses (96%) agreed or strongly agreed that it was appropriate for physicians to discuss end of life issues with patients. Fewer nurses (77%) agreed or strongly agreed that it was appropriate for nurses to discuss these issues with patients.

Only 50% of the nurses agreed or strongly agreed that their patients would be comfortable discussing end of life issues with them. A minority (42%) of the nurses agreed or strongly agreed with the belief that most patients have already discussed end of life issues with their family or significant other.

Whereas 54% of the nurses disagreed or strongly disagreed that discussing end of life issues with patients caused patients anxiety, only 39% agreed or strongly agreed that patients want to talk about such issues. Forty-two percent were unsure if physicians do want nurses to discuss end of life issues with patients.

Table 2

Nurses' Role Perceptions (N=26)

Item	Agree or Strongly Agree n (%)	Unsure n (%)	Disagree or Strongly Disagree n (%)
It is within my role to discuss end of life issues with patients.	21 (81%)	4 (15%)	1 (4%)
I am comfortable discussing end of life issues with patients.	21 (81%)	5 (19%)	0 (0%)
I do not initiate discussions of end of life issues with my patients.	11 (42%)	2 (8%)	13 (50%)
I discuss end of life issues with patients only when they indicate a desire to do so.	22 (85%)	1 (4%)	3 (11%)
It is appropriate for physician to discuss end of life issues with patients.	25 (96%)	0 (0%)	1 (4%)
It is appropriate for nurses to discuss end of life issues with patients.	20 (77%)	3 (12%)	3 (12%)
Most of my patients would be comfortable discussing end of life issues with me.	13 (50%)	8 (31%)	5 (19%)
Most patients have discussed end of life issues with at least one significant other.	11 (42%)	6 (23%)	9 (35%)

Table 2 (Continued)

Nurses' Role Perceptions (N=26)

Item	Agree or Strongly Agree n (%)	Unsure n (%)	Disagree or Strongly Disagree n (%)
Initiating discussions of end of life issues with patients causes them anxiety.	7 (27%)	5 (19%)	14 (54%)
Patients want to talk about end of life issues.	10 (39%)	5 (19%)	11 (42%)
Physicians do not want nurses to discuss end of life issues with patients.	7 (27%)	11 (42%)	8 (31%)

Note. Percentages add to more than 100% due to rounding.

Nurses' Knowledge

The second research question was: To what extent are nurses aware of the existence of and uses for the Durable Power of Attorney for Health Care Decisions? Items pertaining to this research question included items 20-25 To answer this question, frequencies and percentages of responses are reported and discussed (Table 3).

Although the Directive to Physicians, also known as the Living Will, is a legal document in California, only 42% of the nurses agreed or strongly agreed that this was true. The majority (88%) agreed or strongly agreed that it was best to discuss and document advance directives before one became ill. Although the Living Will is not more comprehensive in scope than the Durable Power of Attorney for Health Care Decisions, only 24% of the nurses agreed that this was so.

Fifty percent of the nurses indicated that they did not have a good working knowledge of the Durable Power of Attorney for Health Care Decisions. Although the majority (68%) recognized the accurate definition of the Durable Power of Attorney for Health Care Decisions as a legal document that allows one to designate another to make health care decisions for her or himself if incapacitated, only 50% recognized another purpose as providing immunity for physicians who agree to subordinate their judgement to that of the designated attorney-in-fact.

Table 3

Nurses' Knowledge of the Durable Power of Attorney for Health Care (N=26)

Item	Agree or Strongly Agree n (%)	Unsure n (%)	Disagree or Strongly Disagree n (%)
Directive to Physicians, or Living Will is legal document in California	11 (42%)	7 (27%)	8 (31%)
Best time to discuss and document advance directives is before ill.	23 (88%)	2 (8%)	1 (4%)
Directive to Physicians is more comprehensive than Durable Power of Attorney for Health Care.	7 (28%)	12 (48%)	6 (24%)
I have good working knowledge of Durable Power of Attorney for Health Care.	6 (23%)	7 (27%)	13 (50%)
Durable Power of Attorney for Health Care is legal document allowing naming of surrogate decision maker.	17 (68%)	6 (24%)	2 (8%)
A valid Durable Power of Attorney provides immunity for physician who honors its terms.	13 (50%)	8 (32%)	4 (16%)

Attitudes

The third research question was: What are nurses' attitudes toward end of life issues? The first eight items of the questionnaire were used to address this question. Frequencies and percentages of responses were computed (Table 4).

Only 23% of the nurses responding agreed or strongly agreed that life should be preserved at all cost. An overwhelming 100% agreed or strongly agreed that patients should participate in their health care decisions. Likewise, almost everyone (96%) agreed or strongly agreed that adults have the right to decide what should be done with their bodies, and 92% agreed or strongly agreed that a competent adult is entitled to refuse recommended treatment.

A majority of nurses (62%) agreed or strongly agreed that a basic principle of medical ethics is the preservation of life, but 15% disagreed. Most nurses (85%) disagreed or strongly disagreed that average laypersons have an adequate knowledge of medical technology and are aware of the ways in which life could be artificially extended. Almost all the nurses (92%) agreed or strongly agreed with the wish to avoid having their own lives artificially extended if unable to resume a meaningful life, and 96% intend to participate in making decisions about their own health care.

Table 4

Nurses' Attitudes Toward End of Life Issues (N=26)

Item	Agree or Strongly Agree n (%)	Unsure n (%)	Disagree or Strongly Disagree n (%)
Human life should be preserved at all cost.	6 (23%)	2 (8%)	18 (69%)
Patients should participate in their health care decisions.	26 (100%)	0 (0%)	0 (0%)
Competent adult is entitled to refuse recommended medical treatment.	24 (92%)	1 (4%)	1 (4%)
Basic principle of medical ethics is the preservation of life.	16 (62%)	6 (23%)	4 (15%)
Layperson has adequate knowledge of medical technology and ways life can be extended.	1 (4%)	3 (11%)	22 (85%)
If unable to regain a meaningful life, I would wish to avoid extension of my life.	24 (92%)	1 (4%)	1 (4%)
I expect to share in decision making about my health care.	24 (96%)	0 (0%)	1 (4%)
Competent adults have a right to decide what is done with own body.	25 (96%)	0 (0%)	1 (4%)

Summary

This chapter has provided the findings regarding attitudes of nurses toward end of life issues, nurses' knowledge of the Durable Power of Attorney for Health Care Decisions, and nurses' role perception in discussing end of life issues with patients. Demographic data were also provided.

Chapter 5

CONCLUSIONS AND RECOMMENDATIONS

Conclusions

This study used a descriptive, cross-sectional design to explore nurses' role perception in discussing end of life issues with patients, knowledge of advance directives, and attitudes toward end of life issues. Because individuals may lose their decision making ability when illness or injury occurs, it is important that these individuals have a means to designate health care wishes in the event of incapacitating illness. This study is part of the larger goal of educating nurses and the public about advance directives and stimulating nurses to reflect on their role as patient advocates.

The convenience sample consisted of 26 nurse volunteers from five adult nursing units at a 250-bed hospital in central California. The data collection instrument was a 39 item questionnaire which used open ended and fixed alternative questions to gather demographic data and to explore the sample's knowledge, attitudes, and role perceptions regarding advance directives.

Professional Role

Most nurses (81%) agreed that discussing end of life issues was within their professional role and most (81%) were comfortable with that, although most (85%) discussed

these issues with patients only when patients indicated a desire to do so. Whereas a large majority (96%) indicated that it was appropriate for a physician to discuss end of life issues with patients, a smaller majority (77%) agreed that it was appropriate for nurses to do so.

Although the nurses indicated a willingness to talk to patients, they were less certain that patients want to talk about end of life issues. Only half (50%) of the nurses agreed that most patients would be comfortable discussing end of life issues with them, and only a minority (39%) agreed that patients want to talk about these issues at all.

Other studies, concerned with patient communication with physicians or nurse practitioners, suggested the opposite, that patients wanted to discuss these issues and were relieved to have the chance to do so. Lo et al. (1986) found that 68% of the patients they surveyed wanted discussions (with physicians) about life-sustaining treatment, even if they had negative reactions to thinking or talking about the subject. Johnson and Justin (1988) reported that, during the discussions of a value history which focused on end of life issues, "there was no hesitation on the part of patients to discuss these matters. Many people expressed appreciation that a subject of importance that had not been previously discussed in the office had been introduced" (p. 48).

In the 1986 study by Lo et al., 53% of the patients who wanted discussions about end of life issues wanted the physician to bring up the subject. However, it is inferred that neither the physician nor the patient initiated the discussion, as only 6% of those patients had ever had a discussion of end of life issues with their physician. It is possible, similarly, that patients would like to talk to nurses about end of life issues, especially in the absence of patient/physician dialogue, but expect nurses to bring up the subject. Clarification, through further study, of patients' expectations of nurses and their perception of nurses' roles in discussing and documenting end of life wishes would be useful.

Another factor that might be involved with nurses' decisions about discussing end of life issues with patients is their perception of physician approval or disapproval. In this researcher's study, 42% of the nurses indicated they were unsure whether or not physicians want nurses to discuss end of life issues with patients, and 27% indicated that they perceived that physicians do not want nurses to have that dialogue with patients. This study did not explore the possible relationship between perceived physician approval or disapproval and the decision to initiate this dialogue. However, Murphy (1979) described the bureaucratic model and physician advocate model of nurse-patient relationships, in which the nurse perceives

her first obligation and loyalty is to the institution or physician, rather than the patient. Therefore, physician approval or disapproval might be a factor in nurses' initiation of these important discussions with patients.

It is possible that, given the marked difference in nurses' and patients' perceptions of patient desire to discuss end of life issues, it is the nurses who are actually uncomfortable with that dialogue. This is further supported by the data showing that, although 81% of the nurses indicated they were comfortable discussing those issues, 85% did so only when the patient initiated the discussion. Perhaps nurses view those issues as sensitive subjects to be avoided if possible, thereby not inducing anxiety in either the patient or the nurse.

Only a minority (42%) of the nurses surveyed perceived that most patients had already discussed end of life issues with a family or significant other, whereas Lo et al. (1986) found that 55% of surveyed patients had talked to family members, and Johnson and Justin (1988) found an even higher proportion, 72%. Again, nurses' reported perceptions are not supported by studies of patients. These examples may also indicate a lack of communication between nurses and their patients. Any nurse/patient miscommunication, combined with less than optimal patient/family and patient/physician communication, only adds to the obstacles facing the patient decision maker.

If nurses are acting on inaccurate perceptions of patients' needs, the end result might be that crucial discussion and documentation of patients' end of life wishes do not occur. This could have serious consequences for the patient whose decision making ability is compromised through incapacitating illness.

As the societal trend continues toward autonomous decision making, empowerment of individuals, and the consumer's right to accurate information, it is important for nurses to be prepared to act confidently in their role as patient advocate. Webb (1987) noted that, "Providing people with the knowledge, skills, and confidence to meet their own needs is the highest level of achievement of advocacy" (p. 40).

Nurses' Knowledge

A minority of the nurses correctly identified two factual statements about the Directive to Physicians, also known as the Living Will. More nurses correctly identified two factual statements about the Durable Power of Attorney for Health Care Decisions, although only 23% indicated that they had a good working knowledge of that document.

In view of the low number of nurses who admitted to adequate knowledge of the Durable Power of Attorney for Health Care Decisions, it is possible that the wording of the two items pertaining to that document was leading, thereby being a factor in the discrepancy between the lower

self-assessed knowledge and higher tested knowledge results. It is important to note, however, that the overall knowledge level of the surveyed nurses regarding both advance directives was far below the level necessary to consistently provide accurate and useful information to patients, thus compromising the effectiveness of their role as patient advocates. Although most nurses (88%) agreed that the best time to discuss and document advance directives is before one becomes ill, nurses must be prepared to offer information so that patients can participate.

The data showed that only one subject had a Durable Power of Attorney for Health Care Decisions and/or a Directive to Physicians for his or her personal use, and only 27% had recommended the Durable Power of Attorney for Health Care Decisions to a patient or patient's family in the last year. The lack of knowledge regarding advance directives may be related to the low incidence of personal use and professional recommendation of those documents.

This lack of knowledge and lack of professional recommendation of advance directives has important implications for nursing education and patient care. In order for a nurse to function as a patient advocate when end of life issues are involved, he or she must be knowledgeable about advance directives, current legal trends, and patient rights. If a patient does not have

accurate information about his or her options and rights, the patient's needs are not being met. Similarly, if nurses are not able to inform patients or obtain information for patients about those issues, the nurses are not functioning fully in their role as patient advocates.

Nursing education that focuses on the role of patient advocate, communication skills, information about advance directives, and enhancement of autonomy in nursing practice would be useful in increasing nurses' role perception of patient advocate. Likewise, public education about use of advance directives, patient rights, theoretical and practical aspects of autonomous decision making, and empowerment of the individual would all ultimately benefit the individual who wishes to assert autonomy in decision making.

Attitudes toward End of Life Issues

A majority of nurses agreed that patients should participate in their health care decisions (100%), that adults have the right to decide what should be done with their bodies (96%), and that a competent adult is entitled to refuse recommended treatment (92%). Only a small minority (23%) indicated that life should be preserved at all cost. Most nurses (62%) agreed that the preservation of life is a basic principle of medical ethics, and 85% did not think that the average layperson had an adequate knowledge of medical technology and the ways in which life

can be artificially extended. Patients who wish to participate in their health care decisions but do not have accurate knowledge on which to base their decisions have their autonomous decision making abilities seriously compromised. Nurses, in the role of patient advocates, can intervene by providing accurate information or by ensuring that someone provides it.

Nearly all the nurses surveyed (92%) did not want their own lives artificially extended if unable to resume a meaningful life, and nearly all (96%) expected to participate in decisions about their own health care. These findings were consistent with data obtained by Johnson and Justin (1988) in a study of healthy adult patients, which indicated that 100% of the participants also expected to share in health care decisions and that most feared becoming "victims of technology" (p. 40) when asked about continued life support regardless of prognosis.

Recommendations

The following recommendations are made based on the findings of this study:

1. This study should be repeated using open-ended questions to elicit information on role perception, attitudes, and knowledge, in addition to the fixed response questions. This would allow for a more sensitive and individual measure of these items.

2. Items 20, 22, 24, and 25 could be better answered as objective questions. Additionally, questions regarding nursing specialty and type of unit should have fixed choices to make categorization of demographic data simpler.

3. Further research to explore patients' willingness and comfort in discussing end of life issues and advance directives with staff nurses should be conducted.

4. The study should be replicated with a larger sample from other geographical areas and other clinical specialties.

Summary

Advance directives, particularly the Durable Power of Attorney for Health Care Decisions, offer a powerful way to maintain control over difficult end of life issues. Studies indicate that patients wish to discuss issues related to their death and ways to make their health care wishes known. Yet, the nurses in this study have incomplete data about advance directives and fewer than half perceive that patients want to discuss these issues. Further research and education is imperative to reduce misconceptions about this crucial issue.

Furthermore, for optimal functioning in their role as patient advocates, nurses should have an understanding of basic ethical principles and the ways in which these principles guide the resolution of ethical dilemmas. The principle of respect for autonomy, the ethical foundation

for the Durable Power of Attorney for Health Care Decisions and other advance directives, is the principle that articulates the individual's right to make his or her own decisions, including those that pertain to his or her own life and death. Further education is essential to increase nurses' knowledge of these important principles.

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APPENDIX A

Durable Power of Attorney for Health Care Decisions

DURABLE POWER OF ATTORNEY
FOR HEALTH CARE DECISIONS

(California Civil Code Sections 2410-2443)

WARNING TO PERSON EXECUTING THIS DOCUMENT*

THIS IS AN IMPORTANT LEGAL DOCUMENT. IT CREATES A DURABLE POWER OF ATTORNEY FOR HEALTH CARE. BEFORE EXECUTING THIS DOCUMENT, YOU SHOULD KNOW THESE IMPORTANT FACTS:

1. THIS DOCUMENT GIVES THE PERSON YOU DESIGNATE AS YOUR ATTORNEY-IN-FACT THE POWER TO MAKE HEALTH CARE DECISIONS FOR YOU. THIS POWER IS SUBJECT TO ANY LIMITATIONS OR STATEMENT OF YOUR DESIRES THAT YOU INCLUDE IN THIS DOCUMENT. THE POWER TO MAKE HEALTH CARE DECISIONS FOR YOU MAY INCLUDE CONSENT, REFUSAL OF CONSENT, OR WITHDRAWAL OF CONSENT TO ANY CARE, TREATMENT, SERVICE, OR PROCEDURE TO MAINTAIN, DIAGNOSE, OR TREAT A PHYSICAL OR MENTAL CONDITION. YOU MAY STATE IN THIS DOCUMENT ANY TYPES OF TREATMENT OR PLACEMENTS THAT YOU DO NOT DESIRE.

2. THE PERSON YOU DESIGNATE IN THIS DOCUMENT HAS A DUTY TO ACT CONSISTENT WITH YOUR DESIRES AS STATED IN THIS DOCUMENT OR OTHERWISE MADE KNOWN OR, IF YOUR DESIRES ARE UNKNOWN, TO ACT IN YOUR BEST INTERESTS.

3. EXCEPT AS YOU OTHERWISE SPECIFY IN THIS DOCUMENT, THE POWER OF THE PERSON YOU DESIGNATE TO MAKE HEALTH CARE DECISIONS FOR YOU MAY INCLUDE THE POWER TO CONSENT TO YOUR DOCTOR NOT GIVING TREATMENT OR STOPPING TREATMENT WHICH WOULD KEEP YOU ALIVE.

4. UNLESS YOU SPECIFY A SHORTER PERIOD IN THIS DOCUMENT, THIS POWER WILL EXIST FOR SEVEN YEARS FROM THE DATE YOU EXECUTE THIS DOCUMENT AND, IF YOU ARE UNABLE TO MAKE HEALTH CARE DECISIONS FOR YOURSELF AT THE TIME WHEN THIS SEVEN-YEAR PERIOD ENDS, THIS POWER WILL CONTINUE TO EXIST UNTIL THE TIME WHEN YOU BECOME ABLE TO MAKE HEALTH CARE DECISIONS FOR YOURSELF.

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* Note: This warning (including paragraphs 1-10) must be in at least 10 point bold type in printed forms or all capital letters in typed forms.

5. NOTWITHSTANDING THIS DOCUMENT, YOU HAVE THE RIGHT TO MAKE MEDICAL AND OTHER HEALTH CARE DECISIONS FOR YOURSELF SO LONG AS YOU CAN GIVE INFORMED CONSENT WITH RESPECT TO THE PARTICULAR DECISION. IN ADDITION, NO TREATMENT MAY BE GIVEN TO YOU OVER YOUR OBJECTION, AND HEALTH CARE NECESSARY TO KEEP YOU ALIVE MAY NOT BE STOPPED IF YOU OBJECT.

6. YOU HAVE THE RIGHT TO REVOKE THE APPOINTMENT OF THE PERSON DESIGNATED IN THIS DOCUMENT TO MAKE HEALTH CARE DECISIONS FOR YOU BY NOTIFYING THAT PERSON OF THE REVOCATION ORALLY OR IN WRITING.

7. YOU HAVE THE RIGHT TO REVOKE THE AUTHORITY GRANTED TO THE PERSON DESIGNATED IN THIS DOCUMENT TO MAKE HEALTH CARE DECISIONS FOR YOU BY NOTIFYING THE TREATING PHYSICIAN, HOSPITAL, OR OTHER HEALTH CARE PROVIDER ORALLY OR IN WRITING.

8. THE PERSON DESIGNATED IN THIS DOCUMENT TO MAKE HEALTH CARE DECISIONS FOR YOU HAS THE RIGHT TO EXAMINE YOUR MEDICAL RECORDS AND TO CONSENT TO THEIR DISCLOSURE UNLESS YOU LIMIT THIS RIGHT IN THIS DOCUMENT.

9. THIS DOCUMENT REVOKES ANY PRIOR DURABLE POWER OF ATTORNEY FOR HEALTH CARE.

10. IF THERE IS ANYTHING IN THIS DOCUMENT THAT YOU DO NOT UNDERSTAND, YOU SHOULD ASK A LAWYER TO EXPLAIN IT TO YOU.

1. DESIGNATION OF HEALTH CARE AGENT. I, _____

_____
(Insert your name)

do hereby designate and appoint: Name: _____

Address: _____

Telephone Number: _____

as my attorney-in-fact to make health care decisions for me as authorized in this document.

(Insert the name and address of the person you wish to designate as your attorney-in-fact to make health care decisions for you. None of the following may be designated as your attorney-in-fact: (1) your treating health care provider, (2) an employee of your treating health care provider, (3) an operator of a community care facility, or (4) an employee of an operator of a community care facility.)

2. CREATION OF DURABLE POWER OF ATTORNEY FOR HEALTH CARE.

By this document I intend to create a durable power of attorney by appointing the person designated above to make health care decisions for me as allowed by Sections 2410 to 2440, inclusive, of the California Civil Code. This power of attorney shall not be affected by my subsequent incapacity.

3. GENERAL STATEMENT OF AUTHORITY GRANTED.

In the event that I am incapable of giving informed consent with respect to health care decisions, I hereby grant to the attorney-in-fact named above full power and authority to make health care decisions for me before, or after my death, including: consent, refusal of consent, or withdrawal of consent to any care, treatment, service, or procedure to maintain, diagnose, or treat a physical or mental condition, subject only to the limitations and special provisions, if any, set forth in Paragraph 4 or 6.

4. SPECIAL PROVISIONS AND LIMITATIONS.

(By law, your attorney-in-fact is not permitted to consent to any of the following: commitment to or placement in a mental health treatment facility, convulsive treatment, psycho-surgery, sterilization, or abortion. If there are any other types of treatment or placement that you do not want your attorney-in-fact to have authority to give consent for or other restriction you wish to place on his or her attorney-in-fact's authority, you should list them in the space below. If you do not write in any limitations, your attorney-in-fact will have the broad powers to make health care decisions on your behalf which are set forth in Paragraph 3, except to the extent that there are limits provided by law.)

In exercising the authority under this durable power of attorney for health care, the authority of my attorney-in-fact is subject to the following special provisions and limitations:

_____

_____

_____

_____

5. DURATION.

I understand that this power of attorney will exist for seven years from the date I execute this document unless I establish a shorter time. If I am unable to make health care decisions for myself when this power of attorney expires, the authority I have granted my attorney-in-fact will continue to exist until the time when I become able to make health care decisions for myself.

I wish to have this power of attorney end before seven years on the following date:_____

6. STATEMENT OF DESIRES.

(With respect to decisions to withhold or withdraw life-sustaining treatment, your attorney-in-fact must make health care decisions that are consistent with your known desires. You can, but are not required to, indicate your desires below. If your desires are unknown, your attorney-in-fact has the duty to act in your best interests; and, under some circumstances, a judicial proceeding may be necessary so that a court can determine the health care decision that is in your best interests. If you wish to indicate your desires, you may INITIAL the statement or statements that reflect your desires and/or write your own statements in the space below.)

(If the statement reflects your desires, initial the box next to the statement.)

1. I desire that my life be prolonged to the greatest extent possible, without regard to my condition, the chances I have for recovery or long-term survival, or the cost of the procedures. (_____)

2. If I am in a coma which my doctors have reasonably concluded is irreversible, I desire that life-sustaining or prolonging treatments or procedures not be used. (_____)

3. If I have an incurable or terminal condition or illness and no reasonable hope of long-term recovery or survival, I desire that life-sustaining or prolonging treatments not be used. (_____)

4. I do not desire treatment to be provided and/or continued if the burdens of the treatment outweigh the expected benefits. My attorney-in-fact is to consider the relief of suffering, the preservation or restoration of functioning, and the quality as well as the extent of the possible extension of my life. (_____)

(If you wish to change your answer, you may do so by drawing an "X" through the answer you do not want, and circling the answer you prefer.)

Other or Additional Statements of Desires: _____

_____

_____

_____

_____

7. DESIGNATION OF ALTERNATE ATTORNEY-IN-FACT.

(You are not required to designate any alternative attorney-in-fact but you may do so. Any alternative attorney-in-fact you designate will be able to make the same health care decisions as the attorney-in-fact designated in Paragraph 1 above in the event that he or she is unable or unwilling to act as your attorney-in-fact. Also, if the attorney-in-fact designated in Paragraph 1 is your spouse, his or her designation as your attorney-in-fact is automatically revoked by law if your marriage is dissolved.)

If the person designated in Paragraph 1 as my attorney-in-fact is unable to make health care decisions for me, then I designate the following persons to serve as my attorney-in-fact to make health care decisions for me as authorized in this document, such persons to serve in the order listed below:

A. First Alternative Attorney-in-Fact:

Name: _____

Address: _____

_____

Telephone Number: _____

B. Second Alternative Attorney-in-Fact.

Name:_____

Address:_____

_____

Telephone Number:_____

8. PRIOR DESIGNATIONS REVOKED.

I revoke any prior durable power of attorney for health care.

(YOU MUST DATE AND SIGN THIS POWER OF ATTORNEY.)

I sign my name to this Statutory Short Form Durable Power of Attorney for Health Care on _____ (Date) at _____ (City), _____ (State)

_____
(Signature)

(THIS POWER OF ATTORNEY WILL NOT BE VALID FOR MAKING HEALTH CARE DECISIONS UNLESS IT IS EITHER (1) SIGNED BY AT LEAST TWO QUALIFIED WITNESSES WHO ARE PERSONALLY KNOWN TO YOU AND WHO ARE PRESENT WHEN YOU SIGN OR ACKNOWLEDGE YOUR SIGNATURE OR (2) ACKNOWLEDGED BEFORE A NOTARY PUBLIC IN CALIFORNIA.)

CERTIFICATE OF ACKNOWLEDGEMENT OF NOTARY PUBLIC

(You may use acknowledgement before a notary public instead of the statement of witnesses.)

State of California)
) ss.
County of _____)

On this _____day of _____, in the year _____,

before me, _____
(here insert name of notary public)

personally appeared _____
(here insert name of principal)

personally known to me (or proved to me on the basis of satisfactory evidence) to be the person whose name is subscribed to this instrument, and acknowledged that he or she executed it. I declare under penalty of perjury that the person whose name is subscribed to this instrument appears to be of sound mind and under no duress, fraud, or undue influence.

NOTARY SEAL

_____
(Signature of Notary Public)

STATEMENT OF WITNESSES

(You should carefully read and follow this witnessing procedure. This document will not be valid unless you comply with the witnessing procedure. If you elect to use witnesses instead of having this document notarized, you must use two qualified adult witnesses. None of the following may be used as a witness: (1) a person you designate as the attorney-in-fact, (2) a health care provider, (3) an employee of a health care provider, (4) the operator of community care facility, (5) an employer of an operator of a community care facility. At least one of the witnesses must make the additional declaration set out following the place where the witnesses sign.)

I declare under penalty of perjury under the laws of California that the principal is personally known to me, that the principal signed or acknowledged this durable power of attorney in my presence, that the principal appears to be of sound mind and under no duress, fraud, or undue influence, that I am not the person appointed as attorney-in-fact by this document, and that I am not a health care provider, an employee of a health care provider, the operator of a community care facility, nor an employee of an operator of a community care facility.

Signature:_____ Residence Address:_____
Print Name:_____ _____
Date:_____ _____

Signature:_____ Residence Address:_____
Print Name:_____ _____
Date:_____ _____

(AT LEAST ONE OF THE ABOVE WITNESSES MUST ALSO SIGN THE FOLLOWING DECLARATION.)

I declare under penalty of perjury under the laws of California that I am not related to the principal by blood, marriage, or adoption, and to the best of my knowledge I am not entitled to any part of the estate of the principal upon the death of the principal under a will now existing or by operation of law.

Signature:_____
Signature:_____

SPECIAL REQUIREMENTS

(Special additional requirements must be satisfied for this document to be valid if (1) you are a patient in a skilled nursing facility, or (2) you are a conservatee under the Lanterman-Petris-Short Act and you are appointing the conservator as your agent to make health care decisions for you.)

1. If you are a patient in a skilled nursing facility (as defined in Health and Safety Code Section 1250(c)) at least one witness must be a patient advocate or ombudsman. The patient advocate or ombudsman must sign the witness statement and must also sign the following declaration.

   I declare under penalty of perjury under the laws of California that I am a patient advocate or ombudsman as designated by the State Department of Aging and am serving as a witness as required by subdivision (a) (2)A of Civil Code 2432.

   Signature:_____ Address:_____
   Print Name:_____ _____
   Date:_____ _____

2. If you are a conservatee under the Lanterman-Petris-Short Act (of Division 5 of the Welfare and Institutions Code) and you wish to designate your conservator as your agent to make health care decisions, you must be represented by legal counsel. Your lawyer must sign the following statement:

   I have advised my client _____
   (Name)
   concerning his or her rights in connection with this matter and the consequences of signing or not signing this durable power of attorney and my client, after being so advised, has executed this durable power of attorney.

APPENDIX B

Survey Packet

TO PARTICIPATING NURSES:

This questionnaire is part of my thesis project at San Jose State University for my Master of Science in Nursing Degree.

Please read carefully the next page, the Agreement to Participate in Research at San Jose State University. Please note that this is an ANONYMOUS questionnaire. The signed informed consent sheet should be DETACHED from the questionnaire and returned separately to the collector of the questionnaires. This will ensure the anonymity of the responses.

Your signature indicates that you have read the information and have agreed to participate. You may refuse to participate or cease participation at any time.

Thank you for your assistance.

Pegge Hall

Pegge Hall, BSN

SJSU SAN JOSE STATE UNIVERSITY

A campus of The California State University

School of the Applied Arts and Sciences • Department of Nursing
One Washington Square • San Jose, California 95192-0057 • 408/924-3130

AGREEMENT TO PARTICIPATE IN RESEARCH AT SAN JOSE STATE UNIVERSITY

RESPONSIBLE INVESTIGATOR: Pegge Hall, BSN

TITLE OF QUESTIONNAIRE: Nurse/Patient Communication Survey

I have been asked to participate in a research study that is investigating nurse/patient communication related to end of life issues.

I UNDERSTAND THAT:

1) I will be asked to complete an ANONYMOUS 4-page questionnaire that will be collected and returned in a sealed envelope to the researcher. Total time for my participation should be less than 20 minutes.

2) There are no anticipated risks for participation in this study.

3) A possible benefit of this study to me is receiving information about tools that can be used by myself and my patients for documenting health care wishes.

4) The results of this study may be published, but my identity will remain anonymous throughout this study. My privacy or my job status will in no way be affected by my participation in this study.

5) I will receive no compensation for my participation in this study.

6) Any questions about my participation in this study will be answered by Pegge Hall (815)939-1205. Complaints about the procedures may be presented to Dr. Marcia Canton, thesis advisor (408)924-3173 or Dr. Bobbye Gorenberg, graduate coordinator (408)924-3175. For questions or complaints about research subjects' rights, or in the event of research-related injury, contact Serena Stanford, Associate Academic Vice President for Graduate Studies and Research, at (408)924-2480.

7) My consent is given voluntarily without being coerced; I may refuse to participate in this study or in any part of this study without prejudice to my relations with San Jose State University or the institution at which I am employed.

8) If requested, I will receive a copy of this consent for my files and a copy of the results of this study.

I HAVE MADE A DECISION WHETHER OR NOT TO PARTICIPATE. MY SIGNATURE INDICATES THAT I HAVE READ THE INFORMATION PROVIDED AND THAT I HAVE DECIDED TO PARTICIPATE.

_____ DATE

_____ SUBJECT'S SIGNATURE

_____ INVESTIGATOR'S SIGNATURE

1

NURSE/PATIENT COMMUNICATION SURVEY

Please use the following number scale to respond to statements 1-22. Circle the number in the appropriate column to indicate your degree of agreement or disagreement with each statement.

5-strongly agree; 4-agree; 3-unsure; 2-disagree; 1-strongly disagree

	STRONGLY AGREE		UNSURE		STRONGLY DISAGREE
1. Human life should be preserved at all costs.	5	4	3	2	1
2. Patients should participate in their health care decisions.	5	4	3	2	1
3. Every competent adult has the right to decide what should be done with his or her own body.	5	4	3	2	1
4. A competent adult is entitled to refuse recommended medical treatment despite the opinions of others that such treatment is in his or her best interest.	5	4	3	2	1
5. A basic principle of medical ethics is the preservation of life.	5	4	3	2	1
6. The average layperson has an adequate knowledge of medical technology and is aware of many of the ways in which life can be artificially extended.	5	4	3	2	1
7. In the event that an illness made it very unlikely that I would regain a meaningful quality of life, I would wish to avoid artificial extension of my life.	5	4	3	2	1
8. I expect to participate or share in making decisions about my health care.	5	4	3	2	1

2

For questions 9-19, the term "end of life issues" refers to issues of death and dying, use of life-sustaining treatment, resuscitation status, quality of life, and use of advance directives.

		STRONGLY AGREE		UNSURE		STRONGLY DISAGREE
9.	It is within my professional role to discuss end of life issues with my patients.	5	4	3	2	1
10.	I am comfortable discussing end of life issues with my patients.	5	4	3	2	1
11.	I do not initiate discussions of end of life issues with my patients.	5	4	3	2	1
12.	I generally discuss end of life issues with my patients only when they indicate a desire to do so.	5	4	3	2	1
13.	It is appropriate for a physician to discuss end of life issues with his or her patient.	5	4	3	2	1
14.	It is appropriate for a nurse to discuss end of life issues with his or her patient.	5	4	3	2	1
15.	I believe most of my patients would be comfortable discussing end of life issues with me.	5	4	3	2	1
16.	I believe most of my patients have already discussed end of life issues with at least one family member or significant other.	5	4	3	2	1
17.	Initiating discussions of end of life issues with my patients causes them increased anxiety.	5	4	3	2	1
18.	In general, patients want to talk about end of life issues.	5	4	3	2	1
19.	I believe that physicians do not want nurses to discuss end of life issues with their patients.	5	4	3	2	1
20.	A Directive to Physician, often erroneously referred to as a Living Will, is a legal document in the state of California.	5	4	3	2	1

3

	STRONGLY AGREE		UNSURE		STRONGLY DISAGREE
21. Ideally, the best time for an individual to discuss and document advance directives with appropriate persons is before one becomes ill.	5	4	3	2	1
22. The Directive to Physician is more comprehensive in scope than the durable power of attorney for health care decisions.	5	4	3	2	1
23. I have a good working knowledge of the durable power of attorney for health care.	5	4	3	2	1
24. The durable power of attorney for health care is a legal document that allows an individual to specify his or her health care wishes and to designate another person to make health care decisions for that individual in the event that the individual is no longer able to make his or her own decisions.	5	4	3	2	1
25. A validly executed durable power of attorney for health care decisions is intended to provide immunity from civil and criminal liability to a physician who agrees to subordinate his or her own judgment to that of the designated attorney-in-fact.	5	4	3	2	1

Please answer the following questions by writing in the space provided:

26. Age:_____ 27. Sex:_____ 28. Religion:_____

29. Professional title:_____

30. Nursing specialty: _____

31. Type of unit where you work: _____

32. Number of years you have practiced nursing in California:_____

33. Highest degree obtained in nursing:_____

34. Overall, approximate percentage of patients for whom you provide care that are older than 65 years old: _____%

35. Does your institution have an ethics committee? yes____ no____ unsure____

36. If so, what type of ethics committee(s)? Please check appropriate types:
Nursing _____ Medical _____
Other (please specify) _____

37. Do you have a valid durable power of attorney for health care decisions document for yourself? yes _____ no _____

38. Do you have a valid Directive to Physician document for yourself?
yes _____ no _____

39. Have you recommended the use of the durable power of attorney for health care decisions to one or more patients in the last 12 months?
yes _____ no _____

Please use the remainder of this paper for any additional comments you would like to make regarding this questionnaire and its contents. Thank you for your assistance.

APPENDIX C

Human Subjects Approval

SJSU SAN JOSE STATE UNIVERSITY

A campus of The California State University

Office of the Academic Vice President • *Associate Academic Vice President* • *Graduate Studies and Research*
One Washington Square • San Jose, California 95192-0025 • 408/924-2480

To: Pegge Lee Hall, Nursing
335 West Drummond Drive
Bourbonnais, IL, 60914

From: Charles R. Bolz
Office of Graduate Studies and Research

Date: June 18, 1990

The Human Subjects Institutional Review Board has approved your request to use human subjects in the study entitled:

"Nurses' Perceptions of Their Role in Discussing End of Life Issues with Patients"

This approval is contingent upon the subjects participating in your research project being appropriately protected from risk. This includes the protection of the anonymity of the subjects' identity when they participate in your research project, and with regard to any and all data that may be collected from the subjects. The Board's approval includes continued monitoring of your research by the Board to assure that the subjects are being adequately and properly protected from such risks. If at any time a subject becomes injured or complains of injury, you must notify Dr. Serena Stanford immediately. Injury includes but is not limited to bodily harm, psychological trauma and release of potentially damaging personal information.

Please also be advised that each subject needs to be fully informed and aware that their participation in your research project is voluntary, and that he or she may withdraw from the project at any time. Further, a subject's participation, refusal to participate or withdrawal will not affect any services the subject is receiving or will receive at the institution in which the research is being conducted.

If you have any questions, please contact Dr. Stanford or me at (408) 924-2480.

cc: Marcia Canton, Ph.D.

Dominican
SANTA CRUZ HOSPITAL

AGREEMENT TO PARTICIPATE IN RESEARCH AT SAN JOSE STATE UNIVERSITY

Responsible Investigator: Pegge Hall, BSN

NURSES' PERCEPTIONS OF THEIR ROLE
IN DISCUSSING END OF LIFE ISSUES WITH PATIENTS

Pegge Hall has permission to conduct research at Dominican Santa Cruz Hospital to answer the questions:

1) What do nurses perceive as their role in discussing end of life issues with their patients?
2) To what extent are nurses aware of the existence of and uses for the durable power of attorney for health care decisions?
3) What are nurses' attitudes toward end of life issues?

The results of this study should further our understanding of factors that influence nurses' communication with their patients regarding end of life issues. This study will be conducted from June- December, 1990.

Melody Jones RN MPH CNAA
Vice President

May 21, 1990